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Access

Quality

EOL

Towards quality care at the end of life

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Towards quality care at the end of life

EoL – Towards quality care at the end of life

The policy forum of Palliative Care Australia (PCA)

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A MESSAGE FROM SENATOR CLAIRE MOORE

That we have people of quality, intellect and compassion who are prepared to work in end-of-life care at all levels is crucial. There are many facets to the provision of quality care at the end of life that go to the heart of equity. This publication raises some of these issues and highlights the urgency with which our society must address them, both at a policy level and at a local service delivery level.

As Co-convenor of the Parliamentary Friends of End-of-Life Care Group with Senator Judith Adams, we aim to help raise the issues and keep them on the agenda for the development of good policy to support the provision of quality care at the end of life.

It is important that all of us are brave enough to not only raise but also talk about issues where traditionally silence falls. Silence on uncomfortable

topics does nothing to address the very real issues that affect people at the end of life - a period where issues of equity are exacerbated and where the technicality of immediate physical care is compounded by emotional, social and cultural factors.

SENATOR CLAIRE MOORE

Co-convenor

Parliamentary Friends of End-of-Life Care Group



FROM THE PRESIDENT

Palliative Care Australia's vision is quality care at the end of life for all. Over the past twenty years, palliative care service provision in Australia has come a long way. However, we know that palliative care is still not available to everyone who requires it.

As Australians, we like to think we're all equal, but in reality our access to quality care at the end of life is not equal.

We need to be vigilant in identifying groups who slip through the cracks in the system. We must develop services which meet their needs, rather than simply trying to fit these groups into the existing system.

It is encouraging to see a growing interest across the palliative and end-of-life care sector in providing care for different patient groups including the emerging areas of neurological and chronic conditions. Other groups of people in the community that also seem to miss out include people in rural areas, those with an intellectual or mental health disability and prison populations. There is also great interest, particularly from many of my students, in working with people from culturally and linguistically diverse communities and with Indigenous Australians.

As a developed nation in the Asia Pacific region, Australia also has a responsibility to look beyond its shores to learn from and assist our neighbours in providing quality palliative and end-of-life care for all.

Last year, the Worldwide Palliative Care Alliance identified palliative care as a basic human right as the theme for World Palliative Care Day – this means people wherever they are, should have access to the services they need, when they need them.

This edition of EoL makes an important contribution to identifying a range of issues that are barriers to the provision of quality care at the end of life for all.

PROFESSOR MARGARET O'CONNOR AM

President

Palliative Care Australia



THE ISSUE – EQUITY

Is access to quality palliative and end-of-life care equitable for all Australians?

Palliative and end-of-life care must be available to all who require it, regardless of location, age, income, diagnosis or prognosis, and social and cultural background.¹ But is this the reality today in Australia?

Whilst comprehensive research on this issue is scarce, we do know people dying with cancer are significantly more likely to access specialist palliative care services than those dying with non-malignant conditions. Furthermore, to be Aboriginal, from a culturally or linguistically diverse background, elderly, living in a rural or remote area, or from a socio-economically disadvantaged background reduce one's chance of receiving improved quality of life through the principles and practice of palliative care.²

As such, it can be concluded a significant proportion of people who require access to specialist palliative and end-of-life care do not receive it. This potentially results in unnecessary pain and suffering at the end of life which has implications not only for the patient, but also their family, carers and communities.

Improving access to health care is a universal issue across all levels of the health system. Furthermore, it is a cross-government, intersectoral responsibility. Nevertheless, palliative care services need to examine how they can meet the palliative and end-of-life care needs of the entire community.

In this issue of EoL – *Towards quality care at the end of life*, contributors from across the health sector identify some of the reasons people do not receive access to needs-based care at the end of life, and propose strategies to guide policy debate to deliver on the promise of quality care at the end of life for all.

This edition examines the causes for inequitable access in five key areas.

Income

Socio-economic status has a clear correlation with health outcomes. People who are unemployed and

have low education levels experience higher rates of death from preventable illness and chronic disease. Regions that have high levels of socio-economic disadvantage may experience higher demand for care at the end of life.

Location

People in rural and regional areas face challenges accessing health care – this is exacerbated at the end of life. Location can also apply to care setting – do people who end up in acute care settings receive care at the end of life that maximises quality of life?

Social or cultural background

Indigenous Australians and people from culturally and linguistically diverse backgrounds are underrepresented in the patient populations of palliative care services. Two contributors discuss why this is so and what can be done to address the situation.

Age

Both the elderly and the young face barriers accessing palliative and end-of-life care.

Diagnosis or prognosis

Whilst people dying with cancer generally have well-established pathways to palliative care, people dying with other conditions such as Parkinson's disease and motor neurone disease face unique barriers to accessing services that optimise their quality of life and that of their families and carers.

This issue takes a traditional approach to the analysis of equity – but equity is broad and cannot be fully investigated in a matter of pages. More research is required addressing the experiences and unique needs of specific populations, such as people who have intellectual disabilities or mental disorders.

¹ Palliative Care Australia, *Strategic Plan 2008-2011*, Palliative Care Australia, Canberra, 2008.

² B McNamara, L Rosenwax, C D'Arcy Holman, E Nightingale, *Who receives specialist palliative care in Western Australia – and who misses out*, 2004, University of Western Australia, Perth.

ACCESS – DOES SOCIO-ECONOMIC BACKGROUND MAKE A DIFFERENCE?

- striking disparities within health outcomes exist between socio-economic groups
- models of care have been based on experience with the least disadvantaged
- knowledge of socio-economic indicators is essential to plan appropriate services for local populations

Are palliative care services in Australia accessible to, and providing appropriate care for, all in the community who require their assistance at the end of life?

Each year we understand a little better the looming challenge of providing quality care at the end of life for large numbers of people, and of supporting their families, carers and communities. With this in mind, now is the time for all levels of government to invest in strategies which will develop the entire health system, and the broader community's capacity to provide appropriate care at the end of life.

Whilst palliative care services provide excellent care for their patients, we know that some people in the community find it harder than others to access services and supportive care. Many factors influence an individual's capacity to access needed services. These may include: family structure; geographic location and housing; labour force participation and financial resources; pre-existing disability; literacy and language skills; and ethnicity. In the area of palliative and end-of-life care, the availability of carers and family structure and support are also especially important. Such factors can create barriers to individual access to services and also influence the demand for, or quality of, the care delivered.

Much needs to be understood about the complex relationship between these factors, and an individual's experiences and needs at the end of life. But, what is known is that meeting the needs

of disadvantaged populations requires changes in the volume or type of services delivered to ensure equitable outcomes for all.

This situation is not unique to palliative care. The *Social Health Atlas of Australia* shows the striking disparities within health outcomes that exist between groups of the population. People of low socio-economic status experience worse health outcomes than those of high socio-economic status for almost every cause of mortality and morbidity: and the variation is not only at the extremes, as each lower level of socio-economic status is accompanied by worse health outcomes. There are clear links between lower socio-economic status and higher rates of chronic illness and premature death, including from cancer, cardiovascular disease, cerebrovascular diseases and respiratory system diseases.

Certainly, whilst some of this can be accounted for by individual behaviour, at least fifty per cent of the variation in health outcomes across Australia is related to socio-economic factors.

Until now, palliative and end-of-life care planning and evaluation has been based almost entirely on disease-based projections, for example cancer or broader mortality rates per 100,000 population. Models of care have not accounted for regional or service level variations in the wider determinants of health, for example rates of chronic disease, socio-economic disadvantage, education or ethnicity.



At least fifty per cent of the variation in health outcomes across Australia is related to socio-economic factors.

In order to plan and evaluate services effectively, population-based data on socio-economic factors, health status and risk factors, ethnicity, use of services, and income should be available on a regional and service catchment basis.

Socio-economic indicators of need at the end of life have historically been largely unavailable. Therefore models of care have been based on assumptions derived from experience with those least disadvantaged people who are more likely to access services. This population is likely to have the availability of a full-time carer, lower levels of premature or chronic illness, higher levels of health literacy and sufficient income to cover the costs associated with care at home or in the community.

Planning care for people approaching the end of their lives who have also perhaps been subject to lifelong disadvantage as a consequence of education or socio-economic factors, will require different service models and different ways of providing access. A growing body of published evidence shows that a range of social and psychological factors related to the dynamics and support needs of families and carers are greater determinants of the need for care and service response than the specific diagnosis of the person at the end of life.

Work has been undertaken by the Public Health Information Development Unit (PHIDU) of the University of Adelaide to develop a social health atlas. The *Social Health Atlas of Australia* is a key resource that assists those who plan, evaluate or provide health care services to understand better the relative size and distribution of health needs and health outcomes at a population level.

The atlas, now online at www.publichealth.gov.au, provides detailed information on a regional basis to describe the incidence of social disadvantage and inequality. For palliative care services, this information can help planners understand how demand for services may be greater in areas with

higher levels of chronic illness associated with social and economic disadvantage. It may also help services identify the difficulties that disadvantaged or marginalised groups, currently under-represented in palliative care services, have accessing the care that they need. This can lead to the development of more targeted admission and referral processes to ensure that the most vulnerable in our communities are able to achieve equitable access to care at the end of life.

Addressing the causes of socio-economic disadvantage is a systemic issue, inclusive of the health system but also beyond its borders to the areas of housing, social security, work environments, educational achievement, ethnicity and early childhood development.

Nevertheless, with the data now available, palliative care services can plan for and deliver more appropriate care for the entire population requiring care at the end of life.

JOHN GLOVER
Director

Public Health Information Development Unit



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THE CONVEYOR BELT OF ACUTE CARE – WHAT SHOULD HAPPEN?

- it is usually easier to admit a patient to hospital than find a more appropriate place for care
- advance care planning is required to provide direction for medical staff and families and carers
- greater and more immediate access to specialty palliative care expertise is required in the acute environment

A quiet and largely unpublicised revolution has occurred over the last 30 years in relation to the way we die. The majority of us will now die in acute hospitals. Many will spend their last few days in intensive care surrounded by strangers in an often futile attempt to prolong life by a few more days.

How did this happen?

Faced with sudden illness or deterioration in health in the home or even in institutions, a call to the ambulance is often made. Ambulance personnel do not have any discretion to refuse to take the seriously ill to the emergency department of the nearest hospital, no matter how futile further treatment will be. The emergency department is structured around resuscitation and admission to hospital. Often, there is not enough information to withhold active treatment. Moreover, it is usually easier in a highly pressured environment to admit a patient to hospital rather than find a more appropriate place for end-of-life care. The conveyor belt continues into the acute hospital. If the patient deteriorates further, an urgent call to the intensive care unit is made and the level of care and intervention is even further escalated.

There are many factors driving this conveyor belt. Increasing medical specialisation has resulted in a focus on one particular organ or even, in the case of cardiologists for example, sub-specialising

within a particular organ. The bigger picture is often lost. Instead, there is a focus on what can be done, rather than what should be done. This increasing specialisation doubtless increases the technical skills of the doctor but it can also result in no one physician standing back and assessing the appropriateness of each incremental intervention.

There is also a general reluctance amongst clinicians to discuss end-of-life care issues with patients and their carers. Perhaps this is as a result of a training system which focuses on cure, rather than the inevitable process of ageing and dying. Perhaps it is related to the difficult and time-consuming nature of such discussions. It may also be related to the fact that high technology medicine means that we can prolong 'life'. Specialists who have not specialised in intensive care medicine may not understand the limits of these interventions and find it easier to transfer patients to the intensive care unit rather than begin the discussions around end of life. There is also the fear of litigation when death occurs. As death reviews are one of the few ways we audit a doctor's performance, there may also be pressures to continue active management rather than withdrawing or withholding it.

The fact that over ninety per cent of deaths in the intensive care unit are as a result of withdrawing and withholding treatment may indicate that

The intensive care unit frequently becomes the hospital's palliative care unit. This is not only expensive for our society but can be a cruel way to spend one's last few days.



the intensive care unit has become the hospital's palliative care unit. This is not only expensive for our society at around \$3000 per patient per day but can be a cruel way to spend one's last few days. It is also unfair to offer patients and their relatives false hope.

Many hospitals now operate medical emergency teams which identify and rapidly respond to seriously ill patients. While this system results in improved patient outcomes, the team often becomes the surrogate palliative care team, identifying those who are naturally and inevitably dying, confronting the patient and relatives, often for the first time, with news that nothing further can be done.

The specialty of palliative care usually operates on a referral basis. This works well for patients with terminal conditions such as cancer but many patients die an equally predictable death from other terminal conditions such as heart failure or end-stage respiratory disease. There is early research with palliative care teams operating in much the same way as medical emergency teams, identifying patients who are at the end of life earlier and delivering more appropriate care.

What can be done to prevent patients with a terminal condition being placed on this conveyor belt at the end of life?

Starting in the community, encouraging advance care planning and directives and empowering ambulance services and nursing homes to respect these wishes is the key. This, of course, needs to be accompanied by support for end-of-life care in the home and community.

If patients at the end of life end up in the emergency department, there is a need for a standardised care plan to be immediately implemented which takes the pressure off over-burdened staff and puts the

focus on quality not quantity of life. Resources are needed in the emergency department to make this happen.

The specialty of palliative care needs to expand its role of caring for the dying in areas other than cancer, and their colleagues need greater and more immediate access to palliative care clinicians in the general wards of the hospital in order to provide more appropriate care for patients. This will remove the burden of dealing with dying from super-specialised medical staff.

Specialists need to be discouraged from asking patients and relatives 'whether they want everything done' before consulting intensive care physicians as to the appropriateness of continuing active treatment. Intensive care physicians need to be more involved in the diagnosis and management of dying by being consulted by their colleagues on whether escalation of treatment is appropriate.

Finally, the health system needs to be more transparent with society about the limitations of modern medicine. We often gain the impression from television dramas and the daily reports of yet more miracle drugs and procedures that there will be a cure for most conditions. Eventually, there may be a television series about the inevitability of dying and how, while accompanied by grieving and sadness, it can be a sacred and dignified event.

PROFESSOR KEN HILLMAN
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QUALITY CARE – DOES WHERE YOU LIVE MATTER?

- rural and remote areas have higher rates of chronic disease and lower life expectancy
- health service integration for quality care at the end of life is under-developed in rural areas
- effective models of care in rural areas are required to support people with terminal conditions other than cancer

Improved equity in access to all health services is a common goal of rural communities and their health care providers. Access to services is as important at the very beginning and the end of life as at other times of need. During these times, patients and families need substantial ongoing support, when being close to home, family and community can make critical contributions to lifetime health and wellbeing.

There is increasing demand for end-of-life support across Australia, including in rural, regional and remote areas. In fact, these areas have proportionately older populations, increased rates of mortality and lower life expectancy compared with people in major cities. Around twelve per cent of the population of major cities are over 65 years of age, compared with fourteen per cent in inner regional areas and thirteen per cent in outer regional areas.¹

The trend towards older people concentrating in inner regional areas is increasing, with net movement of people over 65 from major cities as well as both rural and remote areas.²

Death rates are also higher in rural, regional and remote areas. Life expectancy reduces by one to four years with increasing levels of remoteness from major cities. This situation is likely to continue with rural residents having higher rates of chronic diseases such as diabetes, and higher risk factors such as obesity. Even where the prevalence of disease (such as some cancers) is no worse than in metropolitan areas, rural people bear a higher disease burden because of the challenges of accessing health services.

In the embryonic state of development of rural end-of-life care, Australia is no different from many other countries. But unlike some others, Australia has had to contend with a fragmented system, with the division of functions between the Commonwealth and the states and territories.

This fragmentation may be a major hurdle, for quality care at the end of life is demanding in its requirements for high levels of health service integration. It generally requires the involvement and support of the family general practitioner, palliative care nurses, various specialists, nursing,

¹ Australian Institute of Health and Welfare, *Rural, regional and remote health: Indicators of health status and determinants of health*, Australian Institute of Health and Welfare, Canberra, March 2008.

² National Economics, *State of the regions 2008-2009*, Australian Local Government Association, 2009.

Even where the prevalence of disease is no worse than in metropolitan areas, rural people bear a higher disease burden because of the challenges of accessing health services.



pharmacy, other health professionals and social workers, across home-based, primary care, hospital, aged care and specialist palliative care service domains. It must meet the needs and wishes of patients, their families and carers, often over extended periods where the course of the end-of-life condition is unclear.

The foundation of end-of-life care in rural Australia should, as in urban areas, be based on high quality specialist support in the form of both in-patient and home support provided by well-trained health professionals. The primary care sector, through general practice and other members of the primary care team, is also crucial in overall coordinated case management of end-of-life care.

It is pleasing to note that nearly all Rural Divisions of General Practice have taken up Commonwealth-funded rural palliative care projects. Examination of these projects shows that though palliative care services are in various stages of development and have different service models, they share a number of common themes. These include: a focus on better education of health professionals; better links between general practitioners, practice nurses and existing palliative care services; substantially better coordination and communication among specialists, general practice and hospitals in providing services; and the need for general practice to work with the community to build understanding of the options available to patients and their families and carers.³

A generalist approach recognises that end-of-life care applies to all forms of terminal disease and disability. Much of the development of end-of-life care practice has been led by cancer treatment

specialists, with a special emphasis on pain and symptom management, and dedicated hospices and high quality services in this field. However, the leading causes of the higher death rates experienced in regional and remote areas are cardiovascular diseases.

Improvement in end-of-life care will also depend on education and information initiatives to build patient and family participation in choice, especially given the high demands on carers for at-home support. Equity for people in rural Australia will require education that addresses the negative impacts of their well-known stoicism and lower general use of health care services.

It will be crucial that measures to develop people's knowledge, choice and advance care planning for end of life are matched by provision of the resource base to reasonably meet their expectations. For rural people, this will mean systems for after-hours support and advice, especially through telephone and e-health initiatives to overcome distance and isolation, as well as beds and expertise in local hospitals and availability of a wide range of equipment to assist people in their own homes.

A review of the state of end-of-life care in rural Australia in five years' time would be a stern but highly relevant test of the extent to which current health system reforms have measured up in responding to people's needs in this vulnerable time of life.

³ Australian General Practice Network, Rural Palliative Care Program.



THE ASIA PACIFIC – EQUITABLE ACCESS?

- hospice and palliative care development in the Asia Pacific region has been uneven
- building blocks need to be in place for palliative care to develop and flourish

Considerable but uneven progress has been made in the Asia Pacific toward equitable access to palliative and end-of-life care. In 2006 the Worldwide Palliative Care Alliance (WPCA)¹ commissioned a report on levels of palliative care development worldwide. Funding for this was provided by Help the Hospices (UK) and the National Hospice and Palliative Care Organisation (US).

The International Observatory for End-of-Life Care at Lancaster University in the United Kingdom conducted the review which was subsequently published.² This report found that hospice and palliative care development in the Asia Pacific region was notably uneven. Countries like Australia, Hong Kong, Japan, Malaysia, Mongolia, and New Zealand had made significant progress in achieving access to palliative and end-of-life care but most other countries were only in the initial stages of development.

The report classified countries at one of four levels of development:

1. no known hospice-palliative care activity (33%)
2. capacity building activity (18%)
3. localised hospice-palliative care activity (34%)
4. countries where hospice-palliative care services are reaching a measure of integration with mainstream service providers (15%).

Globally by 2006, only fifteen per cent of 234 countries had reached level four. In the Asia Pacific and Oceania the countries reaching level four included Australia, Hong Kong, Japan, Malaysia, Mongolia, and New Zealand. The report provides valuable information but may not be exactly accurate.

Another measure of progress in achieving equitable access was to look at raw numbers of providers of palliative care against the total population. The range of disparity in access from this perspective in the Asia Pacific ranged from one service for every 63,000 people in Australia to one service for almost 158 million people in Pakistan in 2006.

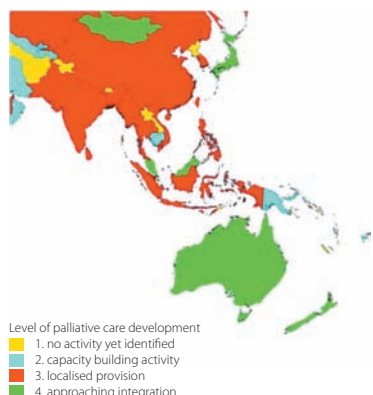
These indicators give us a 20,000-foot view of the issue of equitable access but do not provide a cultural, historical, social, familial, or individual perspective on the challenges faced when developing palliative and end-of-life care in a given country. There are many barriers to palliative care access around the world and in the Asia Pacific. From a public health perspective there are certain building blocks that need to be in place for palliative care to develop and flourish.

These building blocks for palliative care include those identified by the World Health Organization: policy development; opioid availability; and education. In addition, there is a need for: communication infrastructure; implementation and provider scale

¹ The Worldwide Palliative Care Alliance is a global action network focusing exclusively on hospice and palliative care development worldwide. Its members are national and regional hospice and palliative care organisations.

² M Wright, J Wood, T Lynch & D Clark, 'Mapping levels of palliative care development: A global view', *Journal of Pain and Symptom Management*, vol. 35, no. 5, May 2008, pp. 469-485.

Palliative Care Development in the Asia Pacific and Oceania Region



Developed by the International Observatory on End-of-Life Care for the Worldwide Palliative Care Alliance, commissioned by the National Hospice and Palliative Care Organization (USA) and Help the Hospices (UK).

Countries like Australia, Hong Kong, Japan, Malaysia, Mongolia, and New Zealand have made significant progress in achieving access to palliative and end-of-life care but most other countries are only in the initial stages of development.

up; and quality assessment and performance improvement systems to be in place.

For policy development, it is essential that there be some recognition of palliative care in laws, regulations, and planning for health care in the country. Without legal recognition, palliative care lives outside the existing health care system. In addition, the discipline of palliative care needs recognition by the health care professions, including medicine, nursing, social work, and other allied health occupations.

Opioids and other essential palliative care medications are needed for palliative care to be delivered. It is good to provide supportive care when such essential medications are not available but patients cannot achieve the necessary physical comfort, and palliative care is incomplete without effective medications available by mouth as well as parenterally. For pain control the palliative care standard is to use opioids. Unfortunately many countries still severely restrict access to opioids for medical use.

Education is essential to palliative care development. Without education and training health professionals and community members cannot deliver palliative care. Curricula for palliative care are now available in many languages and at different training levels. To achieve equitable access, large numbers of people must be trained. This often takes years to accomplish.

All health care workers ought to have a basic primary level of knowledge regarding palliative care. Those who see many palliative care patients need specialised training and at least a secondary level of knowledge. For those of our patients with complex problems and symptom management needs, we need specialist palliative care experts at tertiary centres.

We live now in an information society so it is also important to have well developed means of communication regarding palliative care. One of the greatest challenges in palliative care development is to reach the public and to engage them on the need for palliative care in our communities. There continues to be great fear of death and all things related to dying. Social marketing methods can be used to engage the public on both the need for palliative care as well as understanding that health care and palliative care are human rights.

As policy is developed, essential medications become available, and education and training programs are implemented, it is necessary to build organisations that can implement and deliver palliative care and those organisations must strive to ensure that the quality of palliative care is both measured, and continuously improved.

The Asia Pacific has much to teach others in all these areas.

STEPHEN CONNOR

Senior Executive
Worldwide Palliative Care Alliance



BRIDGING THE GAP OF INEQUITIES – INDIGENOUS AUSTRALIANS

- the dominant paradigm of ‘whiteman’s’ medicine is antagonistic toward Indigenous perspectives
- a culture-centred approach to care is required to support Indigenous peoples’ preferences
- the authority of a national policy that informs strategic planning for end-of-life care is required

Aboriginal and Torres Strait Islander (Indigenous) peoples struggle every day with advanced or chronic illnesses, premature deaths and compounding grief. Sixty-three per cent of Indigenous Australians suffer serious illness related to, for example, cardiovascular diseases, end stage renal failure, cancer and chronic respiratory diseases. Despite their relatively high morbidity and mortality rates, Indigenous people are more likely to die in hospital without accessing palliative care services or having their cultural needs recognised.

A matter of respect

Bridging the gap of inequities in palliative care for Indigenous peoples begins by respecting the culture. Cultural respect means the recognition, protection and advancement of the inherent rights, cultures and traditions of Indigenous peoples.¹

In practice cultural respect is about allowing Indigenous people to identify their culture, either by having the opportunity to indicate it on admission documents or being asked the question. Indigenous people are empowered when asked ‘what is your culture?’ and ‘do you have any particular requirements we need to know?’. Indigenous people can feel isolated in a health system that does not acknowledge values and beliefs that influence approaches to health and illness care. There is nothing to lose by asking: Indigenous people feel recognised and respected, and non-Indigenous

health care providers stand to broaden their cultural knowledge.

Reciprocal respect

Bridging the gap is a reciprocal process whereby both Indigenous and non-Indigenous health care providers recognise what each can contribute. The compassionate, patient/family-centred ethos that underpins the culture of palliative care, while not incongruent with Indigenous cultural values may be interpreted differently. Indigenous and non-Indigenous health care providers should build relationships that facilitate understanding of cultural differences that influence aspirations relating to end-of-life care. The reciprocal process of respect can enhance palliative care services, offering additional approaches to patient and family care. At the same time, Indigenous communities gain equal access to service and treatment options available to other Australians.

Difference that makes a difference

Fear of separation and being disconnected from spiritual support when admitted to the dominant world of ‘whiteman’s’ medicine leads many Indigenous people to choose to remain in the sanctuary of their community. The concern of Indigenous people is the lack of opportunity to express their cultural needs and negotiate

¹ Australian Health Ministers’ Advisory Council’s Standing Committee on Aboriginal and Torres Strait Islander Health Working Party, *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004-2009*, Department of Health South Australia, Adelaide, March 2004.



Indifference to Indigenous peoples' perspectives of terminal illness and end of life is the basis of disparity in palliative care services for this population.

care requirements within the hospital system. Indifference to Indigenous peoples' perspectives of terminal illness and end of life is the basis of disparity in palliative care services for this population. A critical difference is the interpretation of Indigenous and non-Indigenous holistic paradigms related to end of life.

Different interpretations of the holistic paradigm

Indigenous people view end of life as a significant time when a person passes from the physical to spiritual world. The safe transition of 'life-death-life' requires a balance of the spiritual, physical, emotional, mental, social and cultural attributes of the person. In contrast, the dominant paradigm advocates a hierarchical approach where physical symptoms are prioritised over spiritual and cultural needs. The dominant paradigm is antagonistic toward the Indigenous perspective that end of life and 'passing on' are a spiritual concern paramount in managing physical symptoms. Spirituality and culture are vital constructs of Indigenous identity that should be the central focus of palliative and end-of-life care.

Culture-centred approach

A culture-centred approach means addressing 'what is' rather than 'what ought to be', supporting Indigenous peoples' preferences related to end-of-life care. An example is where services facilitate important cultural practices related to the place of dying. From Indigenous peoples' perspective, the place of dying and death is significant and ideally the patient would be in the 'country' where they are spiritually connected to the land, family and the community. In their own country, the patient can receive care from their family and friends, and have access to 'traditional' medicines and healing if they wish.

When it is impractical for the patient to leave hospital, the palliative care service can help the family to 'bring the country' to the patient. For example, the family may bring local flora, favourite foods, sound and visual recordings of the 'country' and undertake special ceremonies for the patient to experience. In turn, palliative care services can acknowledge Indigenous culture simply by displaying artefacts or other images that the local community can relate to. However, it is important to remember the heterogeneity of Indigenous culture, and that the local Indigenous community should be consulted to ensure the artefacts are appropriate for the region. Public displays of Indigenous art or images convey the organisation's acknowledgment and respect of the local Indigenous community.

Policies for improving palliative care outcomes

Increased awareness of Indigenous issues as a context in palliative care is partly attributed to national programs such as the Indigenous PEPA² and cultural awareness training. In addition, the once taboo topic of dying and 'sorry business' is becoming more acceptable in conversations among Indigenous peoples. However, these advancements are unsustainable without the authority of a national policy that informs strategic planning for end-of-life care in the respective jurisdictions.

A national policy should address inequalities in access to palliative care by Indigenous Australians. A critical component of such a policy is the inclusion of Indigenous peoples' rights to have their culture recognised, respected, protected and honoured, even if this means adapting usual palliative care practice.

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² The Program of Experience in the Palliative Approach, funded by the Australian Government Department of Health and Ageing, offers professional development opportunities for primary care providers from all disciplines to enhance their skills, knowledge and experience in providing end-of-life care.

Palliative Care Australia is currently seeking comment on a draft position statement *Improving access to quality care at the end of life for Aboriginal and Torres Strait Islander Australians*, available on the PCA website.

EQUITY – A VIEW FROM THE MULTICULTURAL FRONT LINE

- new multicultural paradigms are required to address the issue of equity
- the changing multicultural demographic requires health services to innovate their service models
- cultural integrity, based on a new model of multiculturalism, must drive service delivery

Equity is an elusive concept when considering the provision of health care services to Australia's culturally diverse communities.

Equity can be defined as the capacity and willingness of our health services to address the socio-cultural needs and linguistic challenges of contemporary Australia: to be inclusive rather than exclusive; to embrace diversity and consider it an asset rather than a hindrance and barrier.

Equity therefore has an aspirational quality that provides a significant challenge for our institutions and will require a multifaceted approach to achieve the goals we would consider desirable. This challenge is particularly significant when considering palliative care services where issues are exacerbated by deep emotional considerations that characterise end-of-life services and where there is active engagement and participation of families.

The diverse social construct of Australian families requires the adoption of new and innovative strategies to ensure that our health system is relevant and accessible to all. Australia is often described as one of the most culturally diverse societies internationally, yet questions need to be asked. How well do we address cultural diversity issues in service provision? How explicit are we in articulating the underlying principles and values that should underpin policies and practices in service provision?

Australia is one of only a few countries internationally that has well-developed multicultural social policies. These policies, introduced in the 1970s, are bi-

partisan and only rarely used as points of political division. They have contributed to our current success in developing a comparatively tolerant and integrated community that underpins our social compact.

Yet despite the success of the past thirty years, there are still significant challenges and opportunities particularly for our health care services. They can be summarised thus:

- how do we go beyond the current multicultural paradigms and better address issues of equity in the current environment?
- what should be the values and principles that can enrich and strengthen our institutions and services?
- what strategies need to be implemented to achieve these outcomes?

At the moment, there is significant appetite for health care reform in Australia. The Australian Government has embarked on an ambitious reform agenda with an emphasis on equity, particularly addressing the challenges of closing the equity gap for our Indigenous population. This new policy environment is a major opportunity to contribute to the reform of our mainstream health care services.

Firstly then to the issue of developing new multicultural paradigms. Much of our multicultural policies were developed to address social needs arising from Australia's mass migration program (1950s – 1970s) when the Australian economy needed large numbers of largely unskilled migrants

A more fundamental requirement for genuine and sustainable reform of health care institutions is to move beyond the prescriptive approach of cultural generalisations to take account of the social, economic, attitudinal, linguistic and cultural factors that create barriers to equitable access to care.

who found employment in our manufacturing industries. The Australian economy has changed dramatically in the past thirty years resulting in major changes to the composition of our migrant intake.

Australia currently receives approximately 12,000 humanitarian migrants each year, largely refugees. The emphasis now is on skilled and family migration to address skills gaps in our workforce. More recently there has been a growth in temporary migration to address seasonal workforce needs and the part-time contributions of international students in our service industries. These factors now require us to rethink multicultural policy responses and their impact on the type and nature of health care services.

Health care services need to innovate their service models more rapidly to address these quickly evolving needs. Even the training and provision of interpreting is posing a major challenge as the composition of our non-English speaking population becomes more diverse.

A deeper challenge is the cultural factors and values that define our services. At the Centre for Culture, Ethnicity and Health we are developing our ideas around new models of multiculturalism that may be encompassed by the term *cultural integrity*. Cultural integrity in service delivery describes a holistic service response that recognises the diverse cultural and linguistic needs of individual clients. Aspirational and developmental in nature, cultural integrity is relevant in all service settings from the bricks and mortar of hospitals and community health centres to the less conventional approaches of outreach and community education programs.¹

Cultural integrity places the emphasis on human rights and preserves cultural identity and independence. Cultural integrity is about uprightness and ethical

practice that goes beyond just the technical skills and knowledge required to provide high quality health care services.

These new and emerging multicultural paradigms require significant shifts in thinking about solutions. Access to services and promoting equity will require major institutional reform, one aspect of which is employing a more diverse health care workforce that can more intuitively address cultural factors. Further investment in staff training, developing equity policies framed around human rights, and planning services using diversity models and principles are also required. One strategy worth considering is improving the design of health care facilities with the active participation of diverse client groups and a move towards community-based care. This is particularly relevant for people approaching the end of life, many of whom do not want to die in tertiary medical institutions but prefer to be in the community cared for by family.

A more fundamental requirement for genuine and sustainable reform of health care institutions is to move beyond the prescriptive approach of cultural generalisations to take account of the social, economic, attitudinal, linguistic and cultural factors that create barriers to equitable access to care. Service systems and institutions need to strengthen their relations with Australia's diverse community through active programs of community engagement based on the principles of mutual respect and valuing diversity. This will require a fundamental shift in our values and attitudes to our clients and communities.

DEMOS KROUSKOS

Director

Centre for Culture, Ethnicity and Health



¹ This definition of cultural integrity has been provided by Michal Morris, Executive Manager, Centre for Culture, Ethnicity and Health.

Palliative Care Australia is currently seeking comment on a draft position statement *Palliative care and culturally and linguistically diverse communities*, available on the PCA website.

CHILDREN WHO DIE – MISSING OUT ON THE CARE THEY NEED?

- the small patient population has implications for research and evidence base
- palliative care must find a way to work with families who need to maintain hope
- existing models of palliative care struggle to cope with the prognostic uncertainty that characterises many of the conditions that affect children

'Any society, any nation, is judged on the basis of how it treats its weakest members ... the last, the least, the littlest.' Roger Cardinal Mahony 1998.

It is well documented that children with eventually fatal conditions continue to suffer significantly from pain, fear and a range of other physical, psychological and emotional problems. Their families also suffer greatly, both during the child's illness and long into bereavement. Despite this, the provision of palliative care to children has received far less attention and funding than it deserves.

Although the key elements of paediatric palliative care have been described by a number of peak bodies throughout the world, many children do not receive the care they need. There is a range of barriers to the provision of palliative care to children and if things are to improve, it is critical that these are understood and addressed.

The first barrier is that, although not insignificant, the patient population is small when compared with the number of adults who require palliative care. This has implications for research and therefore the creation of an adequate evidence base. It has also made it difficult for individual clinicians to acquire and develop the requisite skills in paediatric palliative care. Furthermore, small patient numbers

spread over a wide geographic area pose a challenge for service development. This population of children has also remained somewhat hidden, lost among the myriad issues confronting the Australian health care system.

A second and more fundamental barrier is the emotional response health professionals and others have to the dying child. Many diseases of childhood are now either preventable or curable and in this context the death of a child has come to be seen as a failure. Health professionals may develop ways of dealing with this that are not conducive to the application of the principles of palliative care which are to maximise quality of life for patient, family and carers. Examples include denying that the child is dying and continuing to pursue curative therapies when it is clear these will not be successful. Consequently, many referrals to paediatric palliative care services come too late or not at all.

Compounding this is the fact that palliative care is misunderstood by many in the community and more worryingly, by some health care professionals. It is often seen as limited to terminal care, or as 'giving up'. No parent wants to feel they are giving up on their child. Indeed, most parents tend to hold on to the hope that their child might survive



Palliative care for children will not be improved by repeated attempts to articulate elements of best practice.

despite intellectually understanding the prognosis is poor. This may lead them to pursue the plethora of alternative therapies available, sometimes at considerable cost to the child, and themselves. Helping parents make decisions in the best interests of the child is a key task of all health services and providers of paediatric palliative care.

Maintaining hope is important to many families, even if it may be seen by others as 'irrational'. It is little wonder that parents, who are either publicly or privately holding on to the hope that their child will survive, reject offers of support from a service which they identify with care for the dying. While it is important that a parent's hopefulness does not negatively affect their child's quality of life, palliative care must find a way to work with families who need to maintain hope.

Palliative care is also seen by some as a model of care for elderly patients or for those with cancer. While there have been recent efforts to overcome this, it is true to say that hitherto, much of the focus of palliative care has been on patients with malignant conditions. Models of care have evolved with this in mind and this has implications for the paediatric setting where fewer than fifty per cent of those in need of palliative care have cancer. The majority of children in this group suffer from a range of rare conditions many of which result in gradual neuro-degeneration. These children, their families and those who care for them must negotiate a path of uncertainty through multiple life-threatening episodes, any of which could be the terminal event. Caring for these children requires specialist skills, flexibility and a model of care that can cope with such uncertainty.

Palliative care for children will not be improved by repeated attempts to articulate elements of best practice. A strategic approach is required to

overcome the key barriers. Interventions should include:

- ensuring the language of palliative care can accommodate hope and that service models allow for an integrated approach in which elements of palliative care sit alongside ongoing efforts to control or even cure the underlying condition
- ensuring all children with eventually fatal conditions have access to health professionals with specialist skills in paediatric palliative care
- providing sufficient attention to this patient population in policy, quality initiatives and research programs
- measuring the outcomes of care interventions to ensure they meet the needs of children and families
- providing paediatricians with the communication skills, emotional support and knowledge they need to care for children with eventually fatal conditions and make the decisions necessary to enhance quality of life.

The field of paediatric palliative care is developing but most services are currently small and poorly resourced. How we respond to this vulnerable patient population will mark us as a society. Are we content to largely ignore their needs and fiddle around the edges or do we wish to show ourselves to be a compassionate community, willing to make a significant investment to ensure the needs of these children and their families are met?

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TOO LITTLE TOO LATE – CARE FOR OLDER AUSTRALIANS

- chronic conditions more common in older people do not have the same pathways to palliative care
- models of care in residential aged care facilities are barriers to best-practice care for the dying
- harmonisation of advance care planning legislation is required for good practice

Age discrimination in health care is not widely written about in Australia but recent studies suggest that elderly people are receiving inadequate assessment and treatment.

The issue though is not whether older people get less care, but whether they get less care on the basis of their needs compared with other patient groups. The World Health Organization report, *Better palliative care for older people* states ‘a body of evidence is mounting that older people suffer unnecessarily because of widespread under-assessment and under-treatment of their problems’.¹

Among the reasons for these problems, it cites the following: an under-assessment of pain; minimal information and involvement in decision making; inadequate home care and access to specialist services; and a lack of palliative care within nursing and residential homes.

In other studies, Luker and colleagues found that stroke guidelines in an Australian tertiary hospital were more likely to be followed for younger people.² Johnson and Kanitsaki found that older people with mental health problems and people from culturally and linguistically diverse backgrounds have particular needs, but often do not get access to appropriate or sufficient services.³

When it comes to palliative care, older people with cancer in the United Kingdom are less likely to be referred to and use specialist palliative care than

younger people. The situation in Australia seems to be the same, with Rosenwax and McNamara’s Western Australian study finding that a person with cancer is less likely to receive specialist palliative care if they are over 85 years of age or if they are single, widowed or living in a region other than a major city.⁴

The same study showed that sixty-eight per cent of people with cancer received specialist palliative care. However, only eight per cent of people with conditions other than cancer received the same care. Chronic heart failure, respiratory illness, diabetes and renal disease contribute significantly to the burden of disease and mortality for older people.

In our recent study of the experiences of people with chronic and complex conditions, eighty-seven per cent of the 45-85 year old participants had more than one chronic condition. Meeting the palliative care needs of older people with conditions other than cancer is one of the key challenges we face.⁵

The first practical challenge is to decide when palliative care should be considered and how best to implement it, especially when so much of the knowledge and experience relates to cancer. Care providers face challenges in making a sensitive transition from curative to palliative care and, as yet, we have no clinical palliative care standards for conditions other than cancer. Doctors do not like talking to their older patients about palliative care despite evidence suggesting that advance

1 E Davies & I Higginson (eds), *Better palliative care for older people*, World Health Organization, Denmark, 2004.

2 J Luker & K Grimmer-Somers, ‘Factors influencing acute stroke guideline compliance: A peek inside the ‘black box’ for allied health staff’, *Journal of Evaluation in Clinical Practice*, vol. 15, no. 2, April 2009, pp.383-389.

3 M-J Johnstone M-J & O Kanitsaki, ‘Ethnic aged discrimination and disparities in health and social care: A question of social justice’, *Australasian Journal on Ageing*, vol. 27, no. 3, September 2008, pp.110-115.

4 LK Rosenwax & BA McNamara, ‘Who receives specialist palliative care in Western Australia - and who misses out’, *Palliative Medicine*, vol. 20, no.4, 2006, pp.439-445.

The issue though is not whether older people get less care, but whether they get less care on the basis of their needs compared with other patient groups.

care planning is best initiated before the person becomes acutely unwell.

For people living in residential aged care facilities there are additional problems. Hardy and her colleagues found that three out of ten barriers to best care for the dying relate directly to aged care: limited after-hours medical support, trained staff, and support of residential aged care facilities by specialist palliative care services.⁶

There is little participation by general practitioners in advance care planning and palliative care in residential aged care facilities, possibly related to time demands, lack of financial incentive, and difficulty advising people in advance of the best course of care. In South Australia, Brown and her colleagues found that while most states have legislation about advance care planning, it is inconsistent between states and provides little assistance to care facilities in working out how best to put the provisions in place.⁷

Finally and most importantly the knowledge and skills of staff in residential aged care facilities may be insufficient for good palliative care practice. One study in the United Kingdom found that care assistants in nursing homes had little formal education in palliative care or knew about the philosophy and principles of palliative care. They were then often unprepared to give end-of-life care to the residents in their care, leaving older people and their families without the comfort and support offered through good palliative care.

The importance of addressing the need for palliative care for older people cannot be overestimated, but nor can the challenges be underestimated. In the Australian context, the lack of co-ordinated multidisciplinary team work in the management of chronic illness creates waste and misery for the person and their family.

From what we know, older people are indeed less likely to receive good palliative care because of general age discrimination and because they have conditions that are not well embedded in current palliative care practice. While many residential aged care facilities try to provide palliative care, lack of standards, training, and support as part of a multidisciplinary team prevent many from achieving their goal.

The National Health and Hospitals Reform Commission's final report recommends a number of crucial changes to improve older peoples' end-of-life experience, but two areas must be emphasised. Firstly, harmonisation of legislation across states in relation to the management of advance care planning will enable a greater consistency to be reached in achievement of consistent good practice for all older Australians. Secondly, and more importantly to achieve equity for older people, the development of knowledge and expertise in best quality end-of-life care for people living with chronic and complex conditions other than cancer must be a priority.

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5 Menzies Centre for Health Policy, *The serious and continuing policy and practice study*, Australian National University and University of Sydney.

6 J Hardy, D Maresco-Pennisi, K Gilshenan & P Yates, 'Barriers to the best care of the dying in Queensland, Australia', *Journal of Palliative Medicine*, vol. 11, no. 10, 2008, pp. 1330-1335.

7 M Brown, C Grbich, I Maddocks, D Parker, P Roe & E Willis, 'Documenting end of life decisions in residential aged care facilities in South Australia', *Australian and New Zealand Journal of Public Health*, vol. 29, no. 1, 2005, pp.85-90.

MND – A CONDITION FALLING BETWEEN THE CRACKS

- the general belief that palliative care is associated with imminent death can affect timely referral
- MND models of care are required to promote equity of access
- creating partnerships across the health system is a cost effective strategy that is limited by the current health system arrangements

Motor neurone disease (MND) is an eventually fatal condition with treatments that, at present, only offer the potential to slow the disease process. It is a complex disease of progressive loss and increasing disability with an average life expectancy of two to three years.

A palliative care approach is required from diagnosis to ensure that early discussions around future care management and advance care planning are held and optimal symptom management for the person with MND and their family is achieved.¹ Discussions around end-of-life care need to be instigated as soon as the person with MND is ready, preferably before speech is affected, to ensure optimal interaction and communication to address their more profound concerns.

It is very important that people with MND are able to access quality end-of-life care, in their location of choice, based on the needs and wishes of the individual and their family.² The aim is to assist people with MND to maximise quality of life and also to support carers to maintain their own health through a coordinated multidisciplinary team approach.

There are a number of barriers that preclude equitable access to palliative care for people with a diagnosis of MND that stem from:

- patient – the nature of the illness
- family – beliefs and needs

- health professionals – skills and knowledge
- palliative care services – resources
- current health care system – models of care.

The general community continues to equate the introduction of palliative care with imminent death. People diagnosed with MND or their families may be reluctant to accept the terminal nature of MND and resist discussions about palliative care. Primary generalist providers, who may have little knowledge of MND or palliative care, and see their role as one of cure or rehabilitation, may perpetuate these views. Some primary generalist or specialist providers may also be reluctant to refer to palliative care or to include palliative care specialists as part of the multidisciplinary team. Furthermore, in some regional, rural and remote areas of Australia, access to specialist palliative care services may be limited or non-existent.

Prognosis at diagnosis is difficult to predict with certainty. Motor neurone disease is the name given to a group of diseases and rare sub-groups can progress more slowly than others. Palliative care services are often reluctant to take on MND patients due to the uncertain course of the disease and consequent concerns about the high demand for care that MND patients will have on limited resources. Sometimes the traditional focus on cancer care may also be a barrier. Consequently some palliative care services will only support MND patients for the last few weeks of life.

¹ D Oliver, D Walsh & GD Borasio (eds) *Palliative care in amyotrophic lateral sclerosis: From diagnosis to bereavement*, 2nd edn, Oxford University Press, New York, 2006.

² International Alliance of ALS/MND Associations, *Statement of good practice for the management of ALS/MND*, 2007.



Palliative care services are often reluctant to take on MND patients due to the uncertain course of the disease and consequent concerns about the high demand for care that MND patients will have on limited resources.

Care provision for people with MND crosses traditional funding silos including: health; disability; equipment; respite; chronic disease; and aged and palliative care. It also involves a combination of state and federal funding. This system is a major barrier to a coordinated multidisciplinary team approach and equitable access to quality needs-based care.

Education is a key strategy to address equity issues related to access. Palliative Care Australia takes a leading role in educating the community about palliative and end-of-life care. MND Australia provides information on the benefits of palliative care through MND associations nationally. In addition the National Palliative Care Program has helped to promote palliative care and build knowledge and services related to MND.

Primary generalist providers, especially those in rural and remote areas, need MND specific information available in a timely manner. MND Australia offers a range of printed information for providers and information sessions are delivered by MND associations in most states. MND Australia is enhancing this approach by developing online resources to assist all providers to improve their confidence and competence in providing timely and quality end-of-life care to people with MND.

The Motor Neurone Disease Pathway Project, funded by the Victorian Department of Human Services in partnership with MND Victoria, highlights the need for MND specific information and 'top-up' funding for palliative care providers to assist them to provide optimal care to people with MND. This project also confirmed the need for MND key workers within palliative care services. This strategy could easily be applied to support primary health care teams.³

Motor neurone disease associations play a vital role in helping people with MND to navigate the complex health care system and to ensure that appropriate referrals are made in a timely manner. This has resulted in some palliative care services establishing MND models of care, with regular case conferencing, promoting a seamless palliative-led team approach. Specialist neurology-led MND clinics also promote a palliative approach to care by including local palliative care services as part of the multidisciplinary team using telehealth facilities when necessary and available. These are simple strategies that help to minimise duplication and promote integrated multidisciplinary care, collaboration and networking.

Motor neurone disease associations working in partnership with other services including palliative care, volunteers, case management, respite care, equipment and rural and remote providers, is an emerging strategy improving outcomes and overcoming barriers related to access to services. These partnerships are cost effective but restricted to one state or region due to the current health care system.

MND Australia recommends the further development of education and information on palliative care and MND. We also recommend support and funding to translate and promote successful models of MND care nationally. It is essential that people with a diagnosis of MND are able to maximise quality of life and dignity in living and dying. Adopting a national coordinated MND specific palliative strategy would help to promote equity and improve outcomes for all Australians living with MND.

³ Victorian Government Department of Human Services, *Motor neurone disease and palliative care: Interim report on the MND pathway project*, Melbourne, 2008.

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PARKINSON'S DISEASE – JUST TOO HARD?

- **deprescribing at the end of life is inappropriate for people with Parkinson's disease**
- **acute models of care do not have well-established pathways to palliative care when required**
- **palliative care funding systems don't work well to provide access to patients with complex non-malignant illnesses with uncertain prognoses**

Parkinson's disease affects around 73,000 Australians, making it the second most commonly occurring progressive neurological condition in our community. While the majority of people diagnosed are over 65, between 18-20 per cent of those affected are of working age.¹

In advanced Parkinson's, people often experience high levels of disability with complicated medication regimes and methods of administration. Recent medical advances in both treating Parkinson's and concurrent illnesses (that may cause death) have lengthened life span.

Parkinson's disease presents a number of challenges for palliative care, particularly when people living with Parkinson's present with a co-morbidity and are admitted to a palliative care agency. While it is important to acknowledge that staff working in palliative care agencies are very skilled, they often have very little knowledge of Parkinson's and the complex medication regimes needed to support this condition.

People living with Parkinson's enter their end of life typically with years of experience finely tuning their medication regime. The medication regime for Parkinson's is highly individualised and complex, what works for one person may not work for another. However, the push for quality use of medicines promotes deprescribing at the end of life which in many cases is appropriate. This is not the case in Parkinson's. The temptation to cease

or simplify medication regimes is often high, and may result in a worsening of Parkinson's symptoms thereby affecting quality of life.

This challenge can be addressed with some simple guidelines, including discussion with the patient's treating specialist or neurologist before any decision regarding the alteration or cessation of medication is made. Furthermore, with Parkinson's medications, there are often issues with interactions with other medications, particularly antiemetics that may worsen symptoms, and the need to administer medication within specific timeframes.

Unfortunately, it remains that people living with Parkinson's who are reaching the end of their lives are rarely referred to or accepted for palliative care. Many of these services may be uncomfortable in accepting a patient with complex care needs and an unpredictable prognosis. It is equally difficult for treating physicians and patients to predict when the end of life is near, and decide when referral for palliative care is appropriate. The palliative phase may be longer than in other illnesses, and the level of dependence and technical care requirements are often greater in Parkinson's – further adding complexity.

The emergence of programs to help patients and families develop advance care plans and directives is an added consideration, as patients with Parkinson's who wish to withdraw from active management are rarely able to pursue good palliative care.

People living with Parkinson's who are reaching the end of their lives are rarely referred to or accepted for palliative care.



The acute model of care, in which neurology professionals work, rarely supports the discussion of offering palliative care in conjunction with symptom management, although when managing advanced illness this is in fact what they are doing. Additionally, many neurologists may not consider referral to palliative care services because the option has never been there.

To support clinical staff and offer palliative care to people living with Parkinson's there must be a change in the way that both the palliative care sector and neurology manage Parkinson's. Developing a model of care that is collaborative and along a continuum of the progression of Parkinson's will ideally improve choices. There have been positive moves to establish a palliative model of care for people living with Parkinson's in the United Kingdom with palliative care being incorporated into the National Institute of Clinical Excellence *Guidelines for Parkinson's*.² Also the Parkinson's Disease Society in the UK has published consumer information on planning for the end of life.

The Royal College of Physicians has developed an evidence-based guideline for long-term management of neurological conditions incorporating skills from neurology, rehabilitation and palliative care medicine.³ The further development of tools such as the Liverpool Care Pathway for the dying patient to incorporate neurological conditions provides health care staff with a valuable tool to introduce and deliver care according to the principles of palliative care.⁴

The ability to introduce quality palliative and end-of-life care as a choice for people living with long term conditions is important. Under the current palliative care funding streams in Australia, patients with complex non-malignant illnesses

and indeterminable prognoses such as Parkinson's are not able to access palliative care unless death is imminent.

To support the provision of choice, a systemic review of palliative care funding is needed. Conditions such as AIDS and more recently, advanced cardiac and respiratory disease, demonstrate that providing the choice of palliative care can significantly improve quality of life for the patient and their family and carers, without significant additional cost.

Developing a collaborative model of care that provides support along the continuum of the illness that incorporates as needed, neurology, allied health, rehabilitation, community, aged care and palliative care teams, will provide choice and support to the patient and family in a more comprehensive and multidisciplinary manner.

This model also supports extending the competencies of health care personnel and enriching their work. In Australia we currently have the opportunity to critically appraise the approaches adopted by other health care systems, and develop our own using the diversity of skills already existing within our health services - which is perhaps the ultimate challenge.

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² National Collaborating Centre for Chronic Conditions, *Parkinson's disease: National clinical guideline for diagnosis and management in primary and secondary care*, Royal College of Physicians, London, February 2006.

³ Royal College of Physicians, National Council for Palliative Care, British Society of Rehabilitation Medicine, *Long-term neurological conditions: Management at the interface between neurology, rehabilitation and palliative care*, Royal College of Physicians, London, 2008.

⁴ Marie Curie Palliative Care Institute, *What is the Liverpool Care Pathway? Healthcare professionals*, The Marie Curie Palliative Care Institute, Liverpool, July 2008.

Parkinson's Disease Society, *Planning for end of life for people living with Parkinson's*, Parkinson's Disease Society, London, 2006.

QUALITY CARE AT THE END OF LIFE – A VISION AND A PROMISE

In 2007, 137,900 deaths were registered in Australia.¹ For approximately seventy-five per cent of these people, death might have been expected or anticipated.

It is this cohort of the population that is the focus of Palliative Care Australia's mission to influence, foster and promote the delivery of quality care the end of life for all Australians.

All health professionals and the community have a responsibility to care, when required, for people approaching the end of life. Regardless of where that care is provided, it requires a degree of skill and competence in the provision of end-of-life care.

Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, and appropriately skilled and resourced primary generalist, primary specialist and support care providers and the community – working together to meet the needs of all people: needs that are physical, emotional, social, cultural and spiritual.

Quality care at the end of life maximises quality of life through appropriate needs-based care. Needs change over time and the network of services must be responsive and flexible to ensure no patient or family falls between the gaps.

Quality care at the end of life is provided by health professionals along a continuum of care – from primary or generalist care providers to specialist palliative care providers – based on the patient,

carer and family needs and choices, as illustrated below.

Quality standards

The national standards for palliative care, the *Standards for providing quality palliative care for all Australians*, define the expected components of quality for care provided at the end of life.²

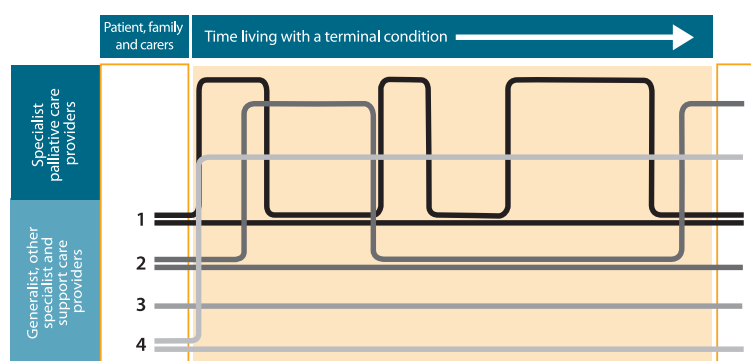
The thirteen national standards express the reasonable expectations for care at the end of life and provide a benchmark for quality.

The future

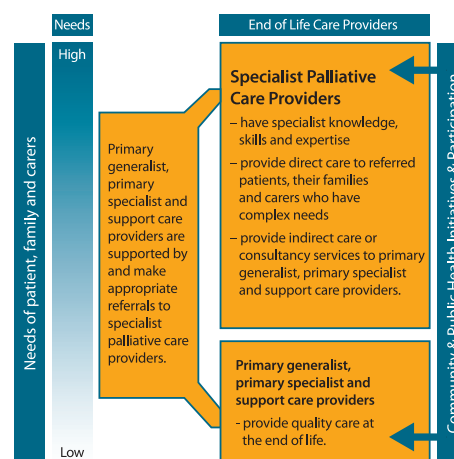
Ensuring the promise of equitable, needs-based quality care at the end of life becomes a reality will require leadership and collaboration across all sectors of the health care system.

The work is focussed on:

- enshrining the right to quality care at the end of life for all Australians in health and social policy
- implementing effective networks of care providers
- ensuring appropriate funding and resourcing
- building the skills of all health care workers to deliver quality care
- developing community capacity to foster caring, supportive communities.



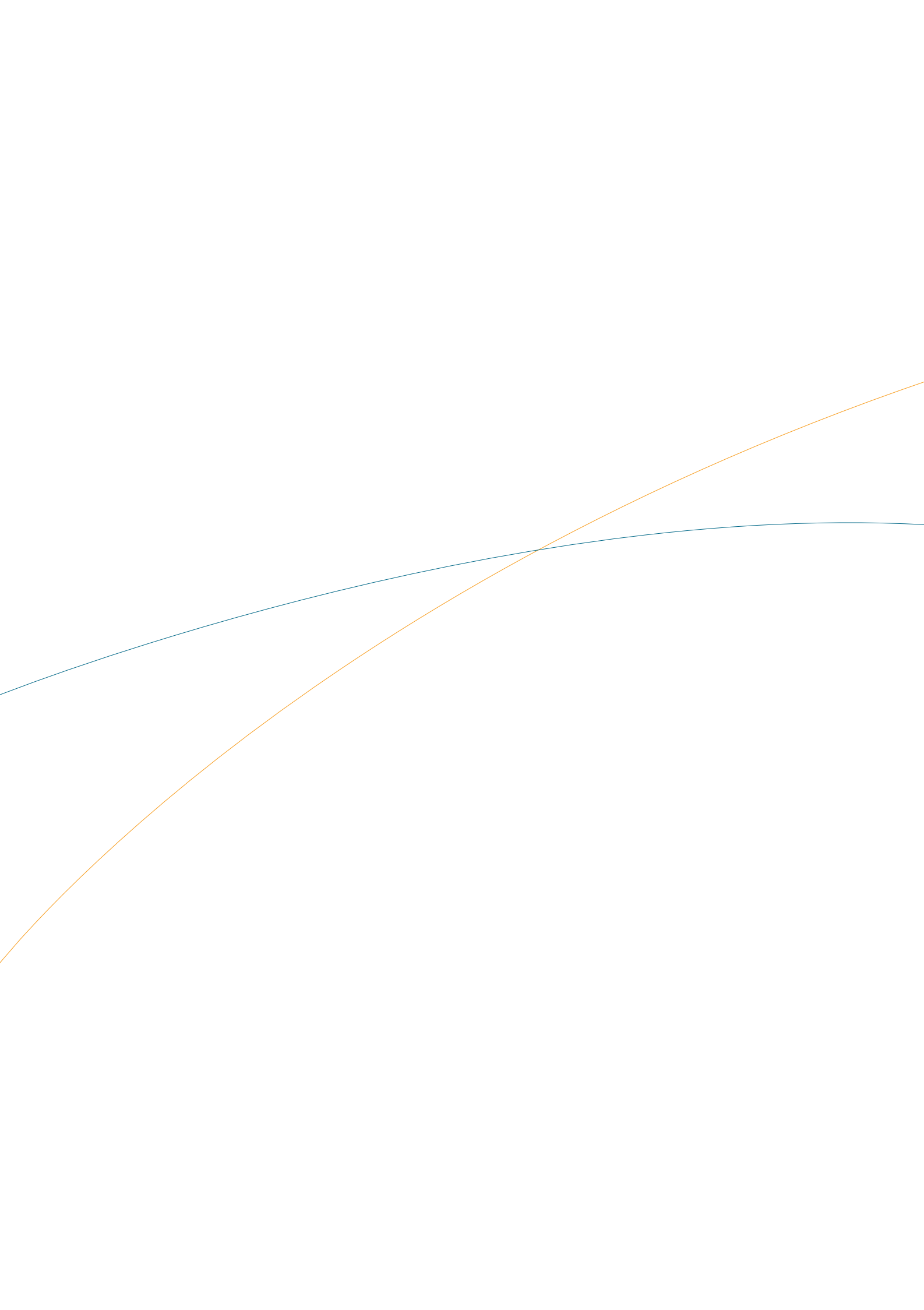
The responsive models of interaction between specialist palliative care providers, primary generalist, primary specialist and support care providers, illustrate the involvement of, and linkages between, all providers of care to meet the changing needs of patients, their families and carers.



The Palliative Care Australia framework for provider networks to deliver quality care at the end of life.

¹ Australian Bureau of Statistics, *Deaths, Australia 2007, 2008*, Canberra.

² Palliative Care Australia, *Standards for providing quality palliative care for all Australians*, 4th edition, 2005, Canberra.





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